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ABSTRACT

Currently, professionals disagree about whether children should be informed about their illnesses and the possibility of their deaths. Some experts feel discussion of these subjects would only upset the children while others feel this knowledge is the children's right and will allay the children's anxieties. What is needed but not available is information about how age influences children's concepts of death. Subjects (N=188) came from three groups: (1) leukemic children; (2) hemophiliac children; and (3) healthy children. Children ranged in age from 3 to 14 years. Intelligence and cognitive stage were measured; children were asked four general questions about death, and ill children's understanding of illness was assessed. The results indicated that the child's sex had no effect on concepts of illness and death while chronological age proved to be a useful index to children's level of comprehension. Although cognitive stage did not provide much more insight, a degree of interrelatedness among the death attributive concepts and the development of death concepts did parallel more general cognitive development. There were no significant differences between healthy children and ill children in their ability to understand death. A strong relationship existed between children's comprehension of illness and concepts of death. The data provides information on precisely what the average child understands about death. (ABL)

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Children's Comprehension of Death

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Fatally Ill Children's Comprehension of Death

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Abstract

This study focused on the manner in which a significant life experience, that of confronting a chronic and potentially fatal illness, affects the development of children's concepts of death. Participating were 188 subjects ranging in age from 3 years 1 month to 14 years 7 months. This sample included leukemic children (a chronic illness that is potentially fatal), hemophiliac children (a chronic illness that is not typically fatal), and healthy children. Results indicated that mental age (chronological age adjusted for performance on an intellectual screening) was the best predictor of death concepts and that children's health status was not significantly related to the development of death concepts. Clinical and theoretical implications were discussed.

Fatally Ill Children's Comprehension of Death

James Aronson (1978), in a retrospective account of a personal bout with pediatric cancer, stressed the "inalienable right" for patients of all ages to be informed, completely and in common language, about the exact nature of their illness, including prognosis and the possibility of death. In the past, many professionals disagreed with this point of view, asserting that since young children cannot comprehend issues of illness and death, discussion of these topics would be unnecessarily upsetting (e.g., Sigler, 1970). More recently, however, others have advocated such discussion, primarily as a means of minimizing children's fears and anxieties (e.g., Spinetta, Swarmer, & Sheposh, 1981). These authors typically suggest discussion at an age-appropriate level so that the child may take full advantage of the information. Consistently lacking, however, are specific data on the levels at which pediatric cancer patients of different ages are able to comprehend concepts of death.

Within the field of developmental psychology, a number of early studies showed that as children age, their concepts of death become more realistic, integrated, and abstract (Anthony, 1971; Childers & Wimmer, 1971; Nagy, 1948). Further studies have led to the prevailing view that concepts of death emerge with the development of essential cognitive structures as described by Piaget (1951; Kane, 1979; Koocher, 1973; Safier, 1964; White, Elsom & Prawat, 1978). These authors typically examined the relationship

between death attribute concepts (such as causation, cessation of bodily functioning, irreversibility, and universality) and other areas of cognitive development such as conservation or animism. General developmental trends were sought and the effects of personal experience were deemphasized or ignored.

A number of authors in the pediatric literature have explicitly stated that despite their physical condition, fatally ill children's cognitive and socio-emotional development continue in a relatively normal fashion, and thus the aforementioned normative models readily apply (e.g., Levine & Herah, 1982). Other authors have more tacitly accepted a normative model for these children and espouse psychosocial interventions based on that notion (e.g., Lane, 1977). While normative data may indeed be useful to understand the views of children with cancer, clinicians should be cautious as the direct parallel has not yet been demonstrated (Koocher & O'Malley, 1981).

Other authors have focused primarily on the unique aspects of fatally ill children's experiences and deemphasized the normative model. As a result of her clinical work, Bluebond-Langner (1978), generated a stage model of such children's concepts of death as related to specific experiences, temporal concerns, life circumstances, and self-concept. While she is to be credited for her attempt to systematically describe the relationship between life experience and concept of death, her work is weakened by the fact that she ignored age and intellectual ability as significant factors and she failed to provide empirical support for her model.

•Also based on clinical experience, Spinetta and Deasy-Spinetta (1981) asserted that seriously ill children's acquisition of death concepts is greatly accelerated as these children demonstrated understanding of their personal mortality that healthy peers typically do not. The authors acknowledged that such notions are based on anecdote and called for more systematic research in the area.

While some researchers have systematically studied death awareness or anxiety in children with cancer (Spinetta, 1974; Waechter, 1971), there have been no controlled studies of death concept development in that population. The present study was an attempt to bridge the gap between the developmental and pediatric literature and will hopefully fill that void. An identical protocol assessing concepts of death was administered to healthy, leukemic, and hemophiliac children. Because childhood cancer is best viewed as a chronic illness with an uncertain outcome (Levine & Hersh, 1982), hemophiliac patients were included as they have a chronic hematologic disorder that is not typically fatal; thus the effects of chronicity and potential fatality could be separated. In addition, variables such as concepts of illness, fears and anxieties, and parental attitudes were assessed. Clearly the results of this study should serve as a useful guide for clinicians as well as provide interesting feedback for cognitive and developmental theorists.

Method

Subjects

A total of 188 children between the ages of 3 years 1 month and

14 years 7 months, representing one of three diagnostic groups, participated in the study. The first group was 44 male and 22 female children who were under treatment for acute leukemia at a large Midwestern children's hospital. Of this group, 63 were Caucasian, two were black, and one was native American. Data on religion and family income were unavailable. Consent for participation was sought from parents while registering their children for regular outpatient appointments. Among the leukemics, 53 (80.3%) were in the first remission at the time of testing, 12 (18.2%) had experienced one or more relapses, and only one (1.5%) had been diagnosed but had not yet attained remission. A risk level for fatality was calculated by medical staff for each subject, yielding 11 (16.7%) having a "good" chance of recovery, 36 (54.5%) having a "moderate" chance, and 14 (28.8%) being at high risk for death. Length of time since initial diagnosis ranged from 3 weeks to greater than 10 years. Subjects were involved in a range of Children's Cancer Study Group (CCSG) protocols and varied widely on frequency and duration of hospitalizations.

The second group of subjects were 28 hemophiliac males followed in the same hematology clinic, 25 of whom were Caucasian and 3 of whom were black. These boys had been diagnosed between 15 months and over 12 years ago. Identical recruitment procedures were followed.

Data on the final 94 subjects were drawn from protocols administered to a group of healthy subjects as part of a previous

study (Walco, 1982). These subjects were 59 boys and 35 girls who were attending Jewish-affiliated schools in middle class neighborhoods. As these data were collected prior to the conceptualization of the present study, no information about illness history was gathered. Furthermore, some measures of cognitive development presently employed were not administered to that sample.

Procedure

All subjects were seen individually in a single session. Administered first were the Similarities and Vocabulary subtests of the age-appropriate Wechsler Intelligence Scales (WISC-R or WPPSI). These subtest scores correlate fairly highly with overall IQ scores and serve as a basic measure of concept formation and abstract verbal reasoning skills.

Cognitive stage was assessed by conservation tasks in three modalities: substance, continuous quantity, and number--unprovoked correspondence (see Goldschmid, 1967). Formal operational thought was measured by performance on Archimedes Test of Floating Objects (Phillips, 1969). Based on their performance on these tasks, subjects were classified as preoperational, concrete operational, or formal operational in their level of cognitive development. Previous work by Walco (1982) indicated that within cognitive stages, children demonstrate a great deal of variability in their comprehension of death. In order to further explore this relationship a host of classification tasks (free sorting, dichotomies, some-all, class inclusion, and combinatorial reasoning; see Hooper, Sipple,

Goldman, and Swinton, 1979) were also administered to leukemic and hemophiliac subjects.

Children were then asked four general questions regarding death which the experimenter took care not to overemphasize. Each question was followed by a series of probe items, thereby facilitating a more thorough assessment of the concept. The general questions were: (a) What makes things die? (b) How can you tell something is dead? (c) How can you make dead things come back to life? (d) Do you think everyone will die someday? These questions address the attribute concepts of causality, cessation of bodily functioning, irreversibility, and universality, respectively. While space prohibits presenting the entire scoring system that was used, Table 1 contains a basic outline for the first concept. For details and reliability data, see Walco (1984/1985).

Insert Table 1 about here

Ill children's comprehension of illness was assessed as both a general concept and in relation to specific aspects of the child's own condition. For the former, a protocol devised by Bibace and Walsh (1979) was employed. For the latter, interview protocols and scoring systems on concepts of leukemia and hemophilia were designed, with a focus on definitions, causes, treatments, and prognoses of these diseases (see Walco, 1984/1985 for details).

Because parental attitudes could mediate the impact of a

child's experience with cancer, a questionnaire was administered to parents. Open-ended questions and those using a five-point Likert scale addressed parents' views of discussing illness and death with their children and retrospective accounts of such discussions.

Finally, because children's fears and anxieties could greatly affect their concepts of death, the Louisville Fear Survey for Children (LFSC; Miller, Barrett, Hampe & Noble, 1972) was administered. This instrument was chosen because factor scores loading on fears of physical injury, natural and supernatural dangers, and psychic stress are available, and it was normed across a similar age group to the current sample.

Results

Prior to subjecting the data to analyses that examine the effects of illness and general cognitive development on concepts of death, a number of preliminary checks were made. First it was established that the sex of the subject had no significant effect on concepts of illness and death. A one-way ANOVA did, however, yield a significant difference between healthy subjects and both leukemics and hemophiliacs on mean scaled scores of Wechsler tests, $F(2,183) = 21.08$, $p < .0001$, with group means of 12.87, 10.35, and 11.02, respectively. Because subsequent attempts to match subjects failed to eliminate this difference, all further analyses involving healthy subjects were conducted with the mean scaled scores as a covariate (Hays, 1973).

Effects of chronological age and diagnosis on concepts of death. In

order to apply analyses of variance with age as an independent variable, this variable was blocked into the following quartiles: 37 to 62 months, 63 to 91 months, 92 to 119 months, and 120 to 175 months. Table 2 shows the means and adjusted group means of the groups for the attribute concepts of death. ANCOVAs revealed significant main effects for age on causality, $F(3,173) = 36.05$, $p < .0001$; cessation of bodily functions, $F(3,173) = 38.99$, $p < .0001$; irreversibility, $F(3,173) = 23.10$, $p < .0001$; and universality, $F(3,173) = 29.63$, $p < .0001$. In all cases, post hoc analyses revealed significant differences between adjacent quartiles with the exception of the last two. Of interest is that none of these analyses revealed significant main or interaction effects for the child's diagnostic group.

Insert Table 2 about here

Effects of general cognitive development on concepts of death.

Analyses of the development of death concepts using performance on conservation and classification tasks as independent variables yielded significant effects for these variables in all cases. Obviously, however, the relationship between cognitive abilities and age (in children) is a linear one and thus the effects of cognitive level may be confounded with other factors associated with age. A recommended strategy to assess the former effects

independently is to conduct analyses with age as a covariate (W. F. Overton, personal communication, February 28, 1983). In so doing, in virtually all cases performance on cognitive tasks failed to produce significant effects. The exceptions were a main effect for performance on conservation tasks on comprehension of cessation of bodily functions, $F(1,178) = 10.88$, $p < .001$, and performance on dichotomies tasks on comprehension of universality, $F(1,89) = 9.25$, $p < .01$.

Finally as a measure of interrelatedness, a correlation matrix of the four attribute death concepts was generated. Correlations ranged from $r = .59$ to $r = .67$, and all were significant at the $p < .0001$ level.

Concepts of Illness. Not surprisingly, analyses of the relationship between age and comprehension of illness as both a general concept and specific to each child yielded significant results. More germane to the present study, however, are the strength of the correlations between illness concepts and death concepts. The general concept correlated with all four attribute concepts, with values ranging from $r = .56$ to $r = .68$, all $p < .0001$. For the specific illness variables, nearly all correlations were significant at the $p < .0001$ level, and values ranged from $r = .32$ to $r = .69$.

Illness related variables. Analyses on the relationship between risk level, stage of the illness, duration of illness, and hospitalizations and concepts of death yielded no significant

findings. Furthermore, correlational data on parents' attitudes and children's concepts of death yielded few significant findings and no clear patterns. Finally, mean T-scores on the LFSC were all within the average range and analyses showed no significant relationship between fear levels and concepts of death.

Discussion

The central issue addressed in this study was the propriety of a normative developmental model for fatally ill children's emerging concepts of death. To this point, the majority of authors in the developmental literature have discussed death concept development in a Piagetian framework, asserting that cognitive stage sets the level at which a child may understand death (Speece & Brent, 1984). Data from the present study only partially support that view.

It was found that chronological age is a very useful index to children's level of comprehension. Age is not, however, an explanatory construct. Unfortunately, the present data do not indicate that cognitive stage provides much more insight as analyses of cognitive stage with age partialled out failed to reach significance. Furthermore, there were a number of cases where children with preoperational concepts of conservation demonstrated operational concepts of death.

The Piagetian framework should certainly not be abandoned, however, as there is clearly a degree of interrelatedness among the death attribute concepts (as demonstrated by correlational data) and the development of death concepts does parallel more

general cognitive development. Rather, the model should be taken less literally; that is, relationships among the various concepts are certainly not direct.

The most dramatic finding in the present study was that there were no significant differences between healthy children and those with chronic and potentially fatal illnesses in their ability to understand death. Thus the anecdotal data indicating that fatally ill children somehow advance more rapidly than their healthy peers was not validated. There are two explanations for this discrepancy. First, the authors apparently spent a great deal of time discussing the notion of death with those children. Had they done likewise with healthy children, similar outcomes might have been found (Walco, 1982). Secondly, the present study focused on death as an abstract concept while some authors are actually describing views of personal mortality. Data from work by Reilly, Hasazi, and Bond (1983) indicate that these may in fact be two distinct concepts. Further research is needed on both of these issues.

The present findings provide practical information for the clinician. It was found that there is a strong relationship between children's comprehension of illness (including specifics of their own condition) and concepts of death. Thus the clinician may opt to begin with discussions of a more innocuous topic, illness, which may provide insights into that child's level of understanding a more sensitive issue, death. Along the same lines, the present study provides specific data on exactly what the average child at a given

age does (and does not) understand about the causality, physical nature, irreversibility, and universality of death. Obviously there is individual variation, but the provided means should serve as a useful clinical guide.

The present study has certain limitations that warrant further research. For example, subjects' religions may influence their views of death and these effects could not be assessed here. In addition, subjects could not be properly matched for estimated I.Q. Given the known neuropsychological effects of many cancer treatments (Zwartjes, Pfefferbaum, & Meadows, 1980), careful studies of concept development as related to chemotherapy and radiation regimens are in order.

Finally, the issue of whether or not these ill children are capable of discussing death may be put to rest. Of the many subjects who participated in this study, only one became overtly upset and his reaction was to the realization that his parents would die one day, not to the prospect of his own mortality! Thus, such conversations may be pursued and hopefully further studies will guide us toward maximizing coping through such exchanges.

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Table 1

Outline of Scoring Criteria for the Attribute Concept of Causality

1. Fantastic, unrealistic or no realistic concept of causality.
2. Partial comprehension. Includes responses that are composed of unrealistic with more realistic concepts or those in which the child's response focuses on agents that may cause death, but there is no elaboration of the causal relationship.
3. Agents or processes that do cause death, but the subject does not provide explanations that indicate direct causality.
4. Multiple cases of level 3 responses.
5. Agents or processes that cause death, and the subject provides explanations that indicate direct causality.
6. Multiple cases of level 5 responses.
7. General means of death that indicate specific and direct causal relationships.
8. Formal, abstract, and principled statements.

Table 2

Means and Adjusted Group Means of Age by Diagnosis on DeathAttribute Concepts

Age Quartile	Health Status			<u>M(adj)</u>
	Healthy	Leukemic	Hemophiliac	
Causality				
1	2.82 (33)	1.25 (8)	2.83 (6)	2.37
2	4.04 (22)	3.43 (21)	3.40 (5)	3.67
3	5.63 (24)	4.69 (16)	5.29 (7)	5.32
4	5.93 (15)	5.28 (21)	5.60 (10)	5.76
<u>M(adj)</u>	4.34	4.06	4.44	
Cessation of Bodily Functioning				
1	2.00 (33)	1.00 (8)	1.83 (6)	1.64
2	3.50 (22)	2.23 (21)	2.60 (5)	2.81
3	4.04 (24)	3.81 (16)	3.71 (7)	3.94
4	4.20 (15)	4.85 (21)	4.00 (10)	4.46
<u>M(adj)</u>	3.26	3.24	3.15	

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Table 2 (continued)

Irreversibility				
1	2.15 (330)	1.13 (8)	2.00 (6)	1.79
2	3.05 (22)	2.52 (21)	2.60 (5)	2.74
3	3.63 (24)	3.48 (16)	3.29 (7)	3.50
4	3.27 (15)	3.76 (21)	3.50 (10)	3.57
<u>M(adj)</u>	2.92	2.88	2.91	
Universality				
1	2.12 (33)	1.00 (8)	2.50 (6)	1.90
2	3.95 (22)	2.95 (21)	2.60 (5)	3.20
3	4.63 (24)	3.88 (16)	4.14 (7)	4.30
4	4.40 (15)	4.95 (21)	4.90 (10)	4.86
<u>M(adj)</u>	3.60	3.45	3.64	

*Note. The number in parentheses is the N of each cell.